

Congress of the United States
Washington, DC 20515

April 5, 2005

The Honorable Ralph Regula,
Chairman
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
2358 Rayburn HOB
Washington, D.C. 20515

The Honorable David R. Obey,
Ranking Member
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
1016 Longworth House Office Building
Washington, D.C. 20515

Dear Chairman Regula and Ranking Member Obey:

As members of Congress committed to improving the health of children and adults in the United States, we respectfully request your support for increased federal funding toward research and public health activities related to Fragile X.

In particular, we seek:

- \$5 million for the National Fragile X Public Health Initiative at the Centers for Disease Control (CDC);
- \$1 million to support ongoing efforts at the Health Resources and Services Administration to develop an appropriate newborn screening model for Fragile X;
- Coordination and translation of available Fragile X research by facilitating and funding the development of promising treatments to include pharmaceuticals and other therapeutic interventions and;
- Strengthening and broadening the scope of international Fragile X research and an increase the number of international Fragile X research collaborations.

Fragile X syndrome is a hereditary condition which causes a wide range of mental impairment, from mild learning disabilities to severe mental retardation. In addition to mental impairment, Fragile X causes a number of physical and behavioral characteristics. Fragile X syndrome is the most common inherited cause of mental retardation and impairment, affecting approximately one in 3,600 males and one in 4,000 - 6,000 females with the full mutation. One in 259 females and one in 700 males are carriers of the premutation.

In FY03 and FY04, the Appropriations Committee urged the CDC to create a Fragile X Public Health Program to conduct surveillance and epidemiological research of Fragile X, as well as provide education to health care professionals and the public on Fragile X and other developmental disabilities. In FY05, \$900,000 was provided to address gaps in current research,

screening, treatment and awareness. Further expansion of the CDC Public Health Initiative will allow for the implementation of a childhood developmental screening model that would include Fragile X. To support the continued growth and development of this important program, we respectfully request \$5 million in funding for the CDC's Fragile X Public Health Initiative.

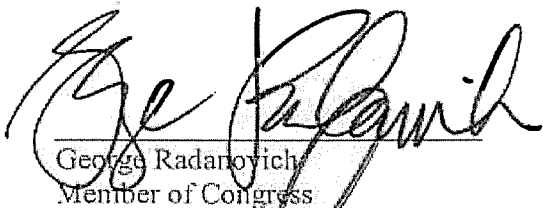
The Health Resources and Services Administration has also been a leading federal partner in the research and development of appropriate technologies to screen for Fragile X in newborns. HRSA has worked with leaders in the scientific community to address the various challenges with screening for Fragile X, which has led to significant progress in the introduction of a viable screening tool. To support the continued efforts of the Health Resources and Services Administration to develop an effective newborn screening tool to appropriately screen for Fragile X, we are seeking \$1 million specifically for this important endeavor.

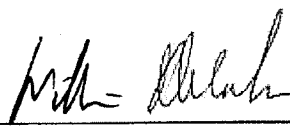
Substantial research has also been privately funded by families and organizations supporting the Fragile X community. Because of these efforts, identifying treatments for Fragile X may have a potential impact on the treatment of related disorders including autism, schizophrenia, and other forms of X-chromosome-linked mental retardation. Therefore, we request that NIH Institutes work together through the NIH Orphan Drug Program and other appropriate vehicles to more fully and rapidly develop these options. In addition, we respectfully request that the Fogarty International Institute at the NIH be encouraged in its efforts to increase the number of international Fragile X projects it funds and to create an international support structure to strengthen and broaden those collaborations.

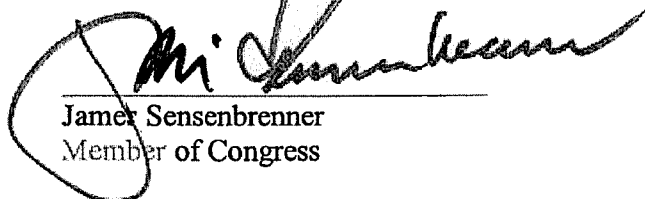
The National Institute of Child Health and Human Development (NICHD) funded three Fragile X Research Centers in March 2003, as a result of The Fragile X Research Breakthrough Act of 2000, in the amount of \$3.75 million. National Institute of Health estimates that its FY 2003 and FY 2004 funding for Fragile X research was \$20 million and \$20.2 million, respectively.

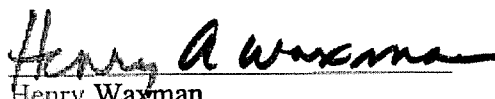
We thank you in advance for your consideration of these important requests. We understand the difficulties the Committee faces this year in prioritizing various requests, but we firmly believe support for continuing and enhancing Fragile X research and public health activities is imperative and urgent given the significant impact of this condition on our communities.


Sincerely,


George Radanovich
Member of Congress

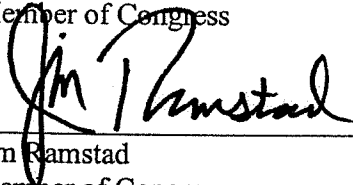

William Delahunt
Member of Congress


James Sensenbrenner
Member of Congress

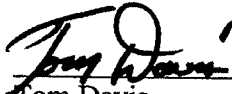

Henry Waxman
Member of Congress



Chris Smith
Member of Congress



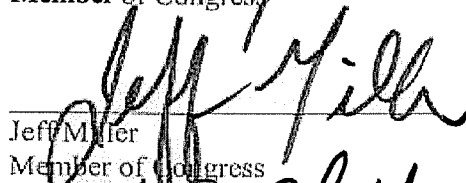
Jim Ramstad
Member of Congress



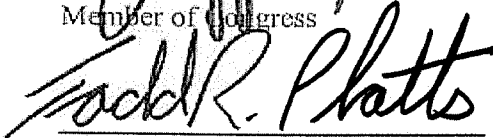
Tom Davis
Member of Congress



Sue Kelly
Member of Congress



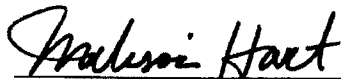
Jeff Miller
Member of Congress



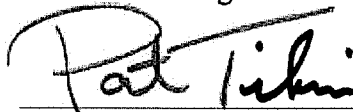
Todd Platts
Member of Congress



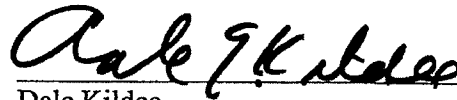
Mike Rogers (AL)
Member of Congress



Melissa Hart
Member of Congress



Patrick Tiberi
Member of Congress



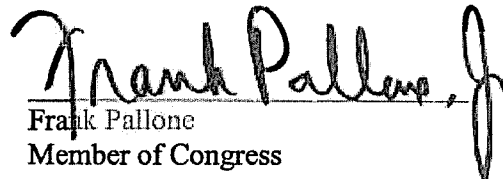
Dale Kildee
Member of Congress



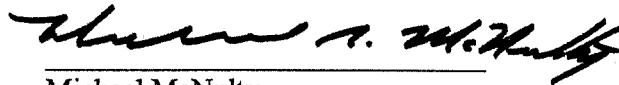
Jim McDermott
Member of Congress



Donald Payne
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Frank Pallone
Member of Congress



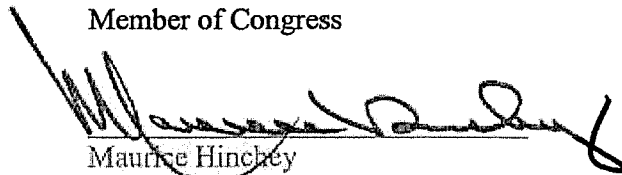
Michael McNulty
Member of Congress



Jim Moran
Member of Congress



Bernard Sanders
Member of Congress



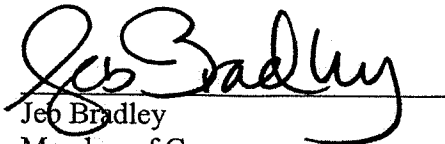
Maurice Hinchey
Member of Congress



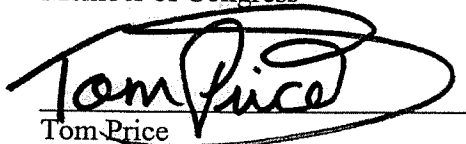
Tim Holden
Member of Congress



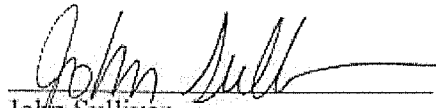
Jim Gerlach
Member of Congress



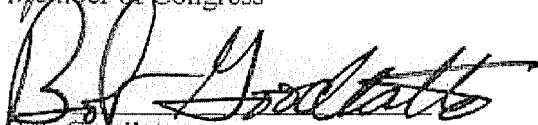
Jeb Bradley
Member of Congress



Tom Price
Member of Congress



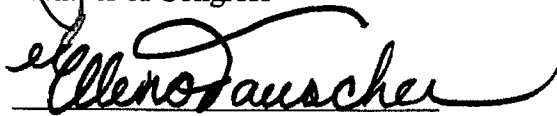
John Sullivan
Member of Congress



Bob Goodlatte
Member of Congress



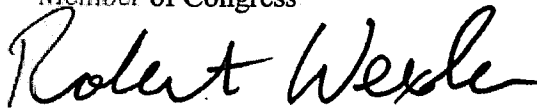
Jim Leach
Member of Congress



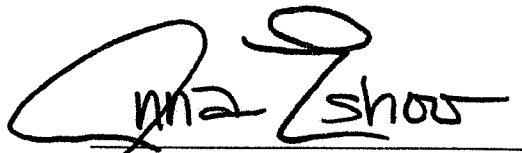
Ellen Taucher
Member of Congress



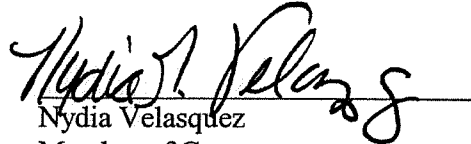
Leonard Boswell
Member of Congress



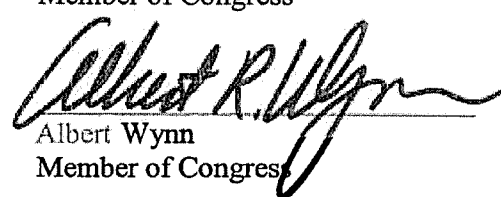
Robert Wexler
Member of Congress



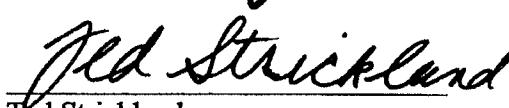
Anna Eshoo
Member of Congress



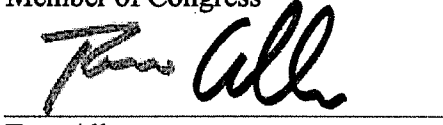
Nydia Velasquez
Member of Congress



Albert Wynn
Member of Congress



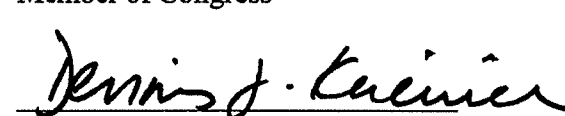
Ted Strickland
Member of Congress



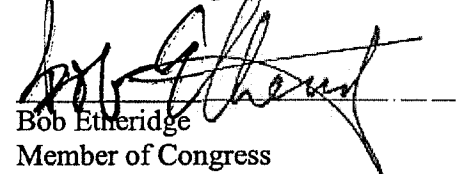
Tom Allen
Member of Congress



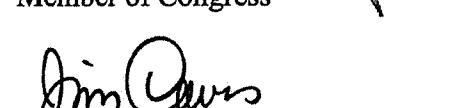
Barbara Lee
Member of Congress



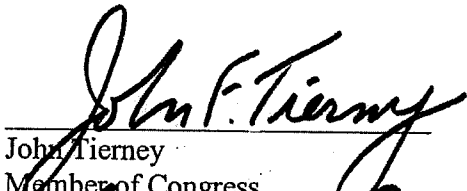
Dennis Kucinich
Member of Congress

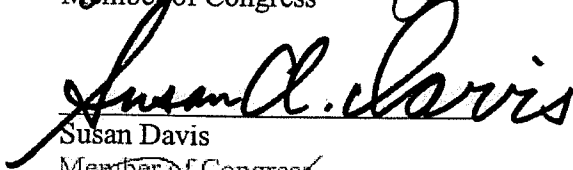


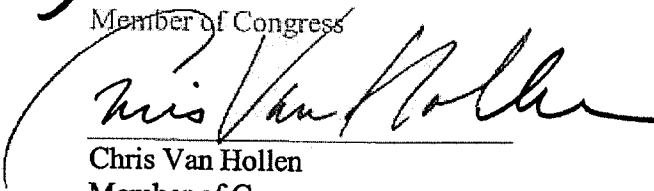
Bob Etheridge
Member of Congress

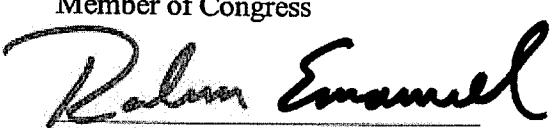


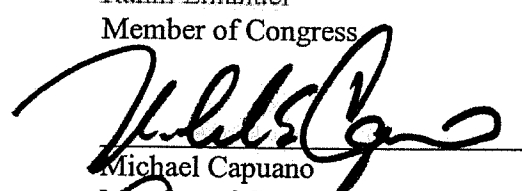
Jim Davis
Member of Congress

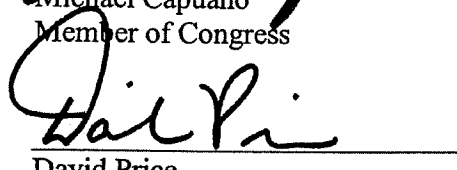

John Tierney
Member of Congress

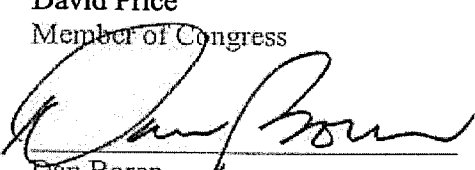

Susan Davis
Member of Congress



Chris Van Hollen
Member of Congress

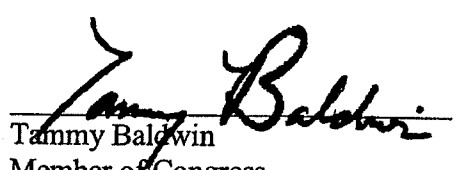

Rahm Emanuel
Member of Congress

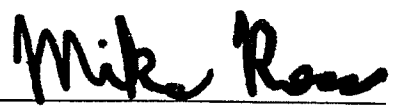

Michael Capuano
Member of Congress



David Price
Member of Congress

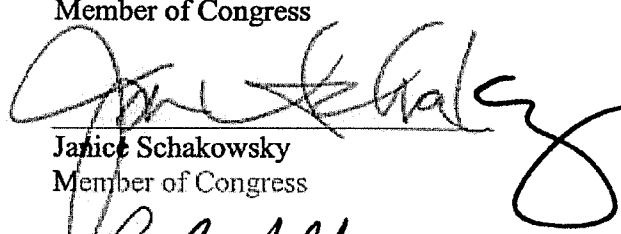

Dan Boren
Member of Congress

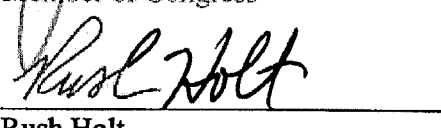

Lloyd Doggett
Member of Congress

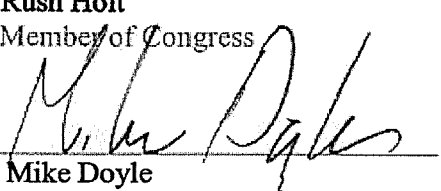

Tammy Baldwin
Member of Congress

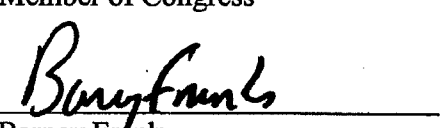

Mike Ross
Member of Congress


Mike Michaud
Member of Congress


Janice Schakowsky
Member of Congress


Rush Holt
Member of Congress


Mike Doyle
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Barney Frank
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